

April 25, 2007 - House Passes Genetic Non-Discrimination Bill Sponsored by Reps. Slaughter & Biggert

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M. Speaker,

Today, it is with great pride that I rise in support of the Genetic Information Nondiscrimination Act, a bill well over a decade in the making. With the passage of this bill, Congress will stand up for the future health of both our citizens and one of medicine's most promising fields: genetic research.

GINA is the culmination of a bipartisan effort to prevent the improper use of genetic information in workforce and insurance decisions.

This problem is no longer simply the work of science fiction writers.

There have been many instances of genetic discrimination: from a woman who was fired after a genetic test revealed her risk for a lung disorder...

...to a social worker, who despite outstanding performance reviews, was dismissed because of her family history of Huntington's disease.

Or consider the case of Heidi Williams, an individual diagnosed with alpha-1 antitrypsin deficiency. In 2004 she testified that a large health insurance company had denied coverage for her two children because they were carriers of alpha-1 antitrypsin disease.

GINA will make these discriminatory practices illegal by prohibiting health insurers from denying coverage, or charging person higher premiums, to a healthy individual because of a genetic predisposition to develop a disease in the future.

GINA also bars employers from using genetic information for hiring, firing, job placement or promotion decisions.

In the 12 years since I introduced the first version of this legislation, the need for it has grown exponentially. Scientific research has advanced so quickly that we cannot afford to wait any longer.

Genetic research offers immense potential for early treatment and prevention of numerous diseases.

Since the sequencing of the human genome was completed in 2003, researchers have identified genetic markers for a wide variety of chronic health conditions and new progress is being made every day.

Fifteen percent of all cancers, for example, have been found to have an inherited susceptibility, and ten percent of adult chronic diseases - like heart disease and diabetes, America's top killers - have a genetic component.

There are already over 15,500 recognized genetic disorders affecting 13 million Americans. Each and every one of us is estimated to be genetically predisposed to between 5 and 50 serious disorders.

And that is exactly why this bill is important to all of us, not just those with recognized disorders. There is not a single person on this planet that carries with them perfect genes - every one of us carries a predisposition to illnesses, and therefore we are all vulnerable to genetic discrimination.

To give you an idea of the potential that exists from this research, consider that genetic tests can tell a woman with a family history of breast cancer if she has the genetic mutation that can cause it, long before the cancer develops.

For these exciting scientific advances to continue, and for the potential of this technology to be realized, we need to make genetic testing something that is commonplace, rather than something that is feared.

But sadly, the threat of genetic discrimination - and the fear of being passed over for promotion, forced to pay more for health insurance, or even being denied coverage - is making men and women less likely to be tested and to take advantage of that potentially life-saving information.

Most importantly, if individuals do not participate in clinical trials, then we will never be able to reap the real benefits of genetic technology.

In a 2006 Cogent Research poll, 66% of respondents said they had concerns about how their genetic information would be stored and who would have access to it.

72% agreed that the government should establish laws and regulations to protect the privacy of individuals' genetic information. And 85% said that without amending current law, employers would use this information to discriminate.

Before I close, I want to reiterate the broad support that this bill enjoys. We have over 220 Democrat and Republican cosponsors behind this bill.

In past Congresses, the Senate has passed this bill twice with unanimous support. And I would like to thank the President who today issued a statement of administration policy in support of the bill.

I want to take a moment to thank the lead Republican cosponsor of this bill, Congresswoman Judy Biggert for her dedication to this bill, along with Congresswoman Anna Eshoo for being a strong advocate for this bill over the years.

I also want to thank Dr. Francis Collins for his support.

His testimonies over the years should have swayed even the firmest unbelievers that genetics has the potential to change our health care system as we know it.

Lastly, I want to thank the advocates from the health and science community. Over 200 organizations including HADASSAH support this bill.

GINA will do more than stamp out a new form of discrimination - it will help our country be a leader in a field of scientific research that holds as much promise as any other in history.

And it will allow us to realize the tremendous potential of genetic research without jeopardizing one of the most fundamental privacies that can be imagined.

M. Speaker, today is a momentous day.

And, I urge all my colleagues to support this bill